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Petersen, Morten Aagaard; Grønvold, Mogens; on behalf of the EORTC Quality of Life Group

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WORK IN PROGRESS

Development of Computerized Adaptive Testing (CAT) for the EORTC QLQ-C30

Morten Aa. Petersen, MS[1], Mogens Groenvold, MD, PhD[1,2], on behalf of the EORTC Quality of Life Group

[1] The Research Unit, Department of Palliative Medicine, Bispebjerg University Hospital, Copenhagen, Denmark
[2] Institute of Public Health, University of Copenhagen, Copenhagen, Denmark

Abstract

The EORTC QLQ-C30 is one of the most widely used health-related quality of life (HRQOL) instruments globally. The Quality of Life Group is developing a new version of the EORTC QLQ-C30 questionnaire based on computerized adaptive testing (CAT). The new CAT instrument will measure the same HRQOL concepts as the QLQ-C30 but with higher precision and flexibility. Currently, the development of CAT item banks for 10 out of 14 dimensions has been completed. Completion of the remaining dimensions is expected during 2013. The new EORTC CAT instrument will be tested in an international clinical validation study starting in 2013.

KEYWORDS

COMPUTERIZED ADAPTIVE TESTING (CAT), EORTC QLQ-C30, HEALTH-RELATED QUALITY OF LIFE, ITEM RESPONSE THEORY (IRT), ITEM BANKING, PATIENT-REPORTED OUTCOMES (PRO)

The EORTC QLQ-C30 is an internationally widely used instrument for assessing health-related quality of life (HRQOL) in cancer patients.[1] The QLQ-C30 assesses 14 HRQOL dimensions as well as overall HRQOL. The EORTC Quality of Life Group (QLG) is currently developing a computerized adaptive testing (CAT)[2] version of the EORTC QLQ-C30.

The basic idea of CAT is to maximize the information obtained through questionnaire administration by adapting the questionnaire to the individual respondent. This is done by using the responses to the previously posed items to select the most informative next item. For example, if a patient has reported severe problems, the next item will be one relevant for patients with severe problems, while if the patient has reported mild problems then the next item will be relevant for patients with mild problems. The administration of items proceeds until a predefined level of precision or a predefined number of items has been reached.

CAT measurement has several advantages compared to classical questionnaire measurement, including increased precision, reduced floor and ceiling effects, avoidance of non-informative questions, and the "questionnaire" can be adapted to each study. The items used in a CAT are selected from a collection of items called an "item pool" or "item bank." As items in an item bank have been calibrated (i.e., fitted) to an item response theory (IRT) model,[3,4] scores based on any subset of the items are comparable, i.e., the score for one patient based on one subset of items can be directly compared to the score for another patient based on a different subset of items.

The EORTC CAT instrument will measure the same well-validated and well-known HRQOL domains/dimensions as measured with the existing EORTC QLQ-C30 (version 3.0). The new items will have the same item and response format as the QLQ-C30 items (i.e., a one week time frame and the response categories "not at all," "a little," "quite a bit," and "very much"). For each QLQ-C30 dimension the CAT instrument will include a unidimensional item bank consisting of items covering the same domain content as the QLQ-C30. This requires development of new items supplementing the existing items in order to fill "gaps" (e.g., items for patients in very poor condition may be lacking). These

procedures will ensure backward-compatibility with QLQ-C30 data collected in earlier studies.

For each QLQ-C30 dimension the item bank development process involves the following steps:

1. Literature search to assess which aspects of the QLQ-C30 dimension the existing subscale measures, and to identify existing items from other instruments that measure the same dimension
2. Development of new items based on the literature search in step 1. The new items should measure the relevant aspects of the dimension and fit the QLQ-C30 item format.
3. Expert evaluations to verify the relevance, appropriateness, and wording of the new items
4. Patient interviews with the same purpose as the expert evaluations
5. Large scale surveys to collect patient responses from a heterogeneous cancer population
6. Psychometric/IRT analyses for the final selection and calibration of items based on the patient responses collected in step 5.

Table 1.

The status of the EORTC CAT item bank development per April 2013.

Dimension	Step 1	Step 2	Step 3	Step 4	Step 5	Step 6
Physical function	√	√	√	√	√	√
Emotional function	√	√	√	√	√	√
Role function	√	√	√	√	√	√
Fatigue	√	√	√	√	√	√
Pain	√	√	√	√	√	√
Insomnia	√	√	√	√	√	√
Lack of appetite	√	√	√	√	√	√
Dyspnoea	√	√	√	√	√	√
Social function	√	√	√	√	√	√
Constipation	√	√	√	√	√	√
Cognitive function	√	√	√	*	-	-
Financial difficulty	√	√	√	*	-	-
Nausea/vomiting	√	√	*	-	-	-
Diarrhea	√	*	-	-	-	-
Overall HRQOL	CAT measurement not currently planned					

Steps 1-6 refer to the development steps described previously.

√ = development completed; * = development in progress; - = development not started yet.

Table 1 summarizes the current status of the item bank development. We have completed the work for 10 of the 15 dimensions of the QLQ-C30. Development is in progress for four remaining dimensions. This work is expected to be completed this year. CAT is not currently planned for the overall health status/quality of life scale, as investigations have indicated that it might be difficult to develop enough relevant, non-redundant items. A total of about 20 researchers from 10 countries in Europe, Taiwan, and Australia have been involved in the work.

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As an example of the item bank development, Table 2 summarizes the development for physical functioning and fatigue (described in detail elsewhere[5-9]). About 40% and 60%, respectively, of the items identified in the literature were judged to measure the "relevant aspects" of the dimension, i.e., one of the aspects measured by the corresponding QLQ-C30 items. Many of these "relevant" items were redundant or were incompatible with the item format used in the QLQ-C30. Using the identified items as inspiration, we were able to construct 71 and 51 new candidate items for the two pools, respectively. The number of candidate items was reduced based on evaluations by international experts and cancer patients. Finally, based on large international samples of cancer patients, psychometric analyses reduced the item banks to 31 and 34 items, respectively. These will constitute the initial versions of the EORTC CAT physical functioning and fatigue item banks.

In collaboration with the Austrian Computer-based Health Evaluation System (www.ches.pro) researchers lead by Bernhard Holzner, an experimental "beta" version of the EORTC CAT software is currently being developed and tested. It includes the completed item banks and will be updated continuously as new item banks become available. The software will allow for secure, web-based collection of the CAT measures as well as clinical and sociodemographic information. Results may also be presented using the software.

The EORTC CAT item banks may also be used to generate so-called "short-forms," i.e., lists of e.g., 5-10 items per dimension that can be used as traditional, "static" paper questionnaires. Results from such short-forms will be fully compatible with the CAT measures, and preserve many of the advantages of CAT. The EORTC CAT item banks must still be viewed as "experimental" as they have not yet been clinically validated. Therefore, they should not yet be used as sole outcome measures in studies. Currently, we recommend using the EORTC CAT item banks together with the original QLQ-C30 primarily for purposes of validating the CAT versions. However, due to the likely improved measurement abilities, including the EORTC CAT may increase the ability to detect important changes and differences. Those interested in using the CAT-software or short-forms may contact the authors (mgro0001@bbh.regionh.dk and mpet0009@bbh.regionh.dk) or visit the EORTC QLG website www.eortc.be/qol for further information.

Clinical and cross-cultural validation of the EORTC CAT is starting in 2013, and will consist of two parts: a feasibility study and a field study. The feasibility study will evaluate the feasibility of web-based administration of the instrument and evaluate whether any changes to the software or layout are required. The main focus of the field study will be on evaluating measurement precision (including sensitivity and responsiveness) of the EORTC CAT, particularly in comparison to the existing QLQ-C30 scales. As both parts will take place in an international setting they will also allow for investigation of possible cross-cultural differences.

With the development of this CAT version of the widely used EORTC QLQ-C30 we expect to clearly improve the measurement precision and flexibility of EORTC assessment of HRQOL in cancer patients. Although the instrument is being developed based on and for cancer patients, we expect that the CAT instrument, as is the case with the QLQ-C30, may be applicable and relevant in many other settings as well.

Table 2.

Development of the physical functioning and fatigue item banks.

	Physical functioning	Fatigue
Step 1	Identified 975 items, 407 items relevant	Identified 588 items, 346 items relevant
Step 2	71 items developed	51 items developed
Step 3	11 items deleted, 12 reformulated → 60 items	7 items deleted, 2 reformulated → 44 items
Step 4	33 patient interviews, 4 items deleted, 12 reformulated → 56 items	52 patient interviews, 0 items deleted, 10 reformulated → 44 items
Step 5	Responses from 1,176 cancer patients	Responses from 1,321 cancer patients
Step 6	31 items included in final item bank	34 items included in final item bank

For more information, please contact:
Morten Aa. Petersen, the Research Unit, Department of Palliative Medicine, Bispebjerg University Hospital, Bispebjerg bakke 23, 2400 Copenhagen NV, Denmark.
Telephone: (+45) 3531 2025.
Fax: (+45) 3531 2071.
Email: mpet0009@bbh.regionh.dk

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PUBLICATIONS...

Individual Quality of Life: Approaches to Conceptualisation and Assessment

By C.R.B. Joyce

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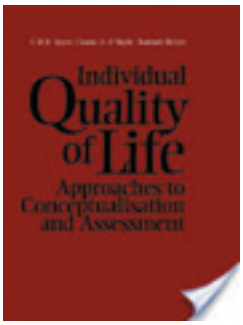

The term "Quality of Life" first came to the explicit attention of the medical profession a little over thirty years ago. Despite the undoubted fact that each one of us has his or her own "quality of life," be it good or bad, there is still no general agreement about its definition, or the manner in which it should be evaluated. Although much has been written about quality of life, this work has been largely concerned with population-based studies, especially in health policy and health economics. The importance of individual quality of life has been neglected, in part because of a failure to define quality of life itself with sufficient care, in part perhaps because of a belief that it is impossible to develop a meaningful method of measuring individual variables.

It is a fundamental belief of the editors of this book that the primary focus of quality of life is and must continue to be the individual, who alone can define it and assess its changing personal significances. The individual perspective is of vital importance not only to patients but to their doctors too, and is more and more frequently proposed as the most meaningful measure of outcome in clinical research, especially in non-remitting or chronic conditions. Workers who wish to consider wider aspects of influences on the illnesses suffered by individuals and the healthcare that they receive will find much to stimulate them in the methods of documentation proposed in this book.

Those mainly concerned with population samples rather than individuals may also find the sensitive methods of investigation proposed here not only to be applicable to their own areas of interest, but also rewarding in perhaps unexpected ways.

How Many More Questions? Techniques for Clinical Interviews of Young Medically Ill Children

By Rochelle Caplan and Brenda Bursch

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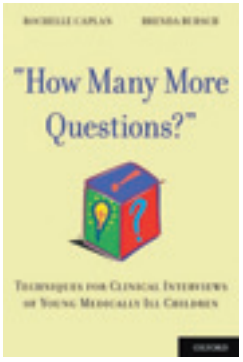

How Many More Questions? Techniques for Clinical Interviews of Young Medically Ill Children provides readers with a comprehensive framework to understand how five-to-ten-year old children use language to formulate and communicate their thoughts. The book then guides the reader in how to effectively elicit information about sensitive and stressful topics from young children, such as their emotions, difficulties, problems, worries, and illness. Seventeen exquisitely written chapters that include twelve developmental guidelines, techniques, case examples, and illustrative dialogues provide the reader with the tools needed to address specific communication challenges involved in speaking with young children who have pain, medical trauma, terminal illness, or specific disorders such as epilepsy. How Many More Questions? is useful for pediatric professionals who strive to acquire exceptional clinical interviewing skills and who no longer wish to hear children say, "When are we done?" The wide range of medical and non-medical professionals who work with young ill children, such as pediatricians, neurologists, psychiatrists, psychologists, neuropsychologists, social workers, nurses, child life specialists, as well as interested parents will use this book as a reference guide.